

HOSPICE CAREGIVING BOOK

FOR YOUR JOURNEY WITH GILCHRIST



PATIENT RIGHTS & RESPONSIBILITIES

BILL OF RIGHTS

Patients of Gilchrist Hospice Care or their guardians have the right to, and Gilchrist caregivers have the responsibility to provide:

1. Information regarding Gilchrist Hospice Care's philosophy of care and a description of the scope of hospice care services and specific limitations of those services.
2. A choice of care providers and the ability to effectively communicate with those providers. The ability to request a change in care provider(s) at any point during the patient's care.
3. Information at the time of acceptance of these rights and of all rules and regulations governing patient responsibilities as evidenced by the patient's written acknowledgment.
4. A choice of an attending physician who will provide the medical direction for their hospice care and to change that physician at any point during their care with us. The attending physician chosen may be a hospice physician.
5. In our inpatient and residential units the medical staff is limited but every attempt will be made to assure that the hospice attending physician is agreeable to the patient. In the event that the attending physician in the inpatient unit is out, the patient or representative will be notified of the name of the covering physician daily.
6. Information at the time of admission regarding services under the hospice benefit and related charges, including any charges for services for which the patient or a private insurer may be responsible.
7. Information regarding all changes in services and to be informed within 15 working days of when the agency becomes aware of a change in coverage.
8. Information regarding one's health condition, unless medically contraindicated. Initial and regular assessments of one's condition and level of comfort, including one's pain level and participation in the planning of services, including treatment measures, management of pain, end of life decisions and referrals to other agencies.
9. Information about diagnosis, prognosis and treatment, including the nature and purpose of any proposed procedures. Communication that is in understandable terms regarding the benefits, risks and effects of the proposed procedures so that an informed decision can be made regarding consent for care.
10. Effective pain management and symptom control from the hospice for conditions related to the terminal illness.
11. The option to refuse treatment to the extent permitted by law and to be informed of the medical consequences of such refusal.
12. The option to refuse to participate in experimental research/treatments.
13. A copy of the organization's written policies and procedures regarding advance directives, including how such rights are implemented by Gilchrist Hospice Care. The option to make advance directives under Maryland state law (e.g. medical orders for life-sustaining treatment (MOLST), living wills, health care treatment directives, durable power of attorney).
14. The option to have confidential treatment of personal health information as outlined in the GBMC/Gilchrist Hospice Care Notice of Privacy Practices.
15. The option to have individual values and beliefs considered in the provision of care including privacy in treatment and personal care.
16. The option to have care that is given without discrimination as to race, color, creed, sex, sexual orientation, disability, religion, ability to pay or national origin.

17. The option to attend or not attend religious services as the patient chooses, and receive visits from members of the clergy.
18. The option to be involved in the resolution of any conflict that may arise regarding care or service decisions.
19. Education to the patient and family regarding the treatment required so that the patient can, to the extent possible, help himself or herself, and the family or other party designated by the patient can understand and help the patient.
20. Admission to services only if the agency has the ability to provide safe, professional care at the level of intensity needed. Patients have the right to reasonable continuity of care and to be referred elsewhere if denied service for any reason.
21. Freedom from verbal, physical, mental, sexual and psychological abuse, including injuries of unknown source, and misappropriation of patient property.
22. Freedom from mistreatment, neglect, involuntary seclusion and exploitation, and to have person and property respected.
23. Freedom from physical and chemical restraints.
24. The option to manage personal financial affairs.
25. The option to maintain legal counsel.
26. The option to register a grievance regarding treatment or care that is, or fails to be, furnished and a lack of respect for property by anyone who is furnishing services on behalf of the hospice and to not be subjected to discrimination or reprisal for exercising his or her rights.
27. To utilize live streaming video to maintain contact, but may not video record or audio record Gilchrist staff, volunteers or treatments.

COMPLAINTS

Our goal is to assist you to meet your physical, psychosocial and spiritual needs during your time in hospice. If you are not satisfied or have a complaint, please discuss it with your nurse or the team manager. If it is not resolved, the following options are available to you:

To register a complaint or patient safety concern with Gilchrist Hospice Care's President, call 443-849-8200; TTY: 1-800-735-2258.

To register a grievance with the State of Maryland, Office of Health Care Quality, without fear of reprisal or discrimination, patients and families may call 1-800-492-6005. The Office of Health Care Quality is available to answer questions related to the agency's Medicare and/or licensure status, or to receive complaints. This service is in operation 24 hours a day, 7 days a week. Normal working hours are 8 a.m. to 4:30 p.m. After 4:30 p.m., calls are taken by an answering machine.

Written Grievances to OHCQ can be sent to:

Office of Health Care Quality,
Maryland Department of Health and Mental Hygiene
Spring Grove Center,
Bland Bryant Building
55 Wade Avenue,
Catonsville, Maryland 21228

To register a grievance with the Community Health Accreditation Program (CHAP), patients and families may call (800) 695-9656 24 hours a day.

Written grievances TO CHAP can be sent to:

Mail: CHAP
Attn: Complaints Department
1275 K Street NW, Suite 800
Washington, DC 20005
On-line: www.chapinc.org/contact-us.aspx
(Select "complaints" from the menu.)
E-mail: complaints@chapinc.org
Fax: (202) 862-3419

An investigation will be conducted by Gilchrist Hospice Care of complaints made by the patient or the patient's family or guardian regarding treatment or care and Gilchrist Hospice Care will document the existence of the complaint and the resolution of the complaint.

INPATIENT CENTER RIGHTS

In the addition to the above rights, patients admitted to any Gilchrist Inpatient or residential facility have the right to, and Gilchrist Caregivers have the responsibility to provide:

1. Privacy, including the right to have a staff member knock on the patient's door to announce his or her presence before entering.
2. Private meetings or visits with any individual the patient chooses in accordance with patient and facility safety.
3. Unlimited contact with visitors and others, and to restrict contact with visitors and others not directly involved in the patient's care.
4. The use of a private telephone within the facility.
5. Access to and use of personal clothing and possessions; and reasonable security for those effects in accordance with the facility's security policies.
6. An environment that preserves their dignity and contributes to a positive self image.

THE PATIENT HAS THE RIGHT TO EXPECT THAT GILCHRIST HOSPICE CARE WILL:

1. Protect and promote the patient's right to exercise his or her rights.
2. Ensure that all alleged violations involving mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property by anyone furnishing services on behalf of Gilchrist Hospice Care, are reported immediately by hospice employees and contracted staff to the hospice administrator.
3. Immediately investigate all alleged violations involving anyone furnishing services on behalf of Gilchrist Hospice Care and immediately take action to prevent further potential violations while the alleged violation is being verified.
4. Take appropriate corrective action in accordance with state law if the alleged violation is verified by the hospice administration or an outside body having jurisdiction.
5. Ensure that verified violations are reported to State and local bodies having jurisdiction within five working days of becoming aware of the violation.

GILCHRIST PATIENTS & FAMILY RESPONSIBILITIES

1. To give accurate and complete information about current complaints, past illnesses, hospitalizations, medications, and other matters relating to the patient's health, as well as advance directive documentation, living will information and who has been chosen to make decisions for the patient should the patient not be able.
2. To assist in developing and maintaining a safe environment by reporting perceived risks in their care and unexpected changes in their condition.
3. To provide information to Gilchrist Hospice Care about service needs and expectations.
4. To ask questions when care, treatment and service or instructions are not understood.
5. To participate in the development and update of the Plan of Care. To consult with Gilchrist Hospice Care prior to making additions or changes to the care plan.
6. To follow the care, treatment and service plan developed. If concerns arise regarding the Plan of Care, to express to Gilchrist Hospice Care the concerns and the ability or willingness to adhere to the Plan of Care. To understand that the anticipated care outcomes may not be achieved if the plan of care is not followed.
7. To follow established Gilchrist Center rules and regulations.
8. To show respect and consideration toward Gilchrist Hospice Care staff and property.
9. To meet financial obligations as agreed in the Gilchrist Hospice Care Service Agreement.
10. To inform Gilchrist Hospice Care when appointments cannot be kept.
11. To provide Gilchrist Hospice Care the name of the attending physician desired to manage their hospice care. This may include a hospice physician.

ADVANCE DIRECTIVES

Advance Directives are legal documents stating the medical procedures you do and do not want in the event you are unable to communicate these wishes yourself. It is important that your wishes are clear should you not be able to make them known.

Advance Directives may include:

1. A Living Will specifies the types of end-of-life care you desire if you are unable to verbalize those wishes at a later time.
2. The Health Care Agent Designation gives another person the authority to make medical decisions for you if you are unable to do so.

PHYSICIAN ORDERS

A MOLST form (Medical Orders for Life Sustaining Therapy) states whether you want CPR (Cardiopulmonary Resuscitation) attempted or the Limited Care or Comfort Care options, which are defined below:

Life-Prolonging Care:

(MOLST Option 1)

CPR tries to get your heart to beat again if it stops. This means pressing on your chest and using an electric shock to attempt to restart your heart. Most of the time in patients with an advanced disease, CPR does not work.

If you want CPR attempted, you will also agree to have a ventilator or breathing machine to keep breathing if necessary. This involves putting a tube down your throat into your lungs and connecting you to machine that pushes air into your lungs. You cannot eat or talk while on this machine. If you are on a ventilator, you will likely need very strong medicines. These are usually given in the intensive care unit (ICU). CPR will not cure your disease and in most patients with an advanced disease, CPR does not return you to your previous state of health. With the Life-Prolonging approach, you choose to have these procedures in exchange for the possibility of a longer life.

Limited Care:

(intubation-MOLST Option A-1)
or (BiPap- MOLST Option A-2)

With this approach, prolonging life is still important, but **not if it means having CPR or being placed on a breathing machine.** If you choose Limited Care, you may choose to have a breathing tube inserted (intubation) or a pressure mask (BiPap) if needed. And agree to medicines for treatable problems that may arise such as fluid in the lungs or a urinary infection. This approach lets you have different medical treatments including hospital care, antibiotics, other medicines, and fluids through a vein. You choose to avoid CPR and to allow death to occur naturally.

Comfort Care:

The main goal of this approach is to not prolong life; it is to maximize comfort, relieve symptoms and allow death to occur naturally. Treatments are only used if they help control uncomfortable symptoms such as pain, trouble breathing, or feeling sick to your stomach. It does not include CPR and breathing machines. Nor does it normally include hospitalization – unless it is needed to provide comfort. If you choose Comfort Care, you will be treated at home, an inpatient hospice, a nursing home, or other facility until death occurs naturally.

NEED TO COMPLETE ADVANCE DIRECTIVES?

Tell your Gilchrist social worker. They will help you to complete the forms and answer questions.

ALREADY HAVE ADVANCE DIRECTIVES?

First, review to make sure all wishes for nutrition, hydration, resuscitation, and transportation have not changed. Second, have two copies of all written documents available. One will be reviewed by your Gilchrist team and the other will be added to your medical record.